

Review of Pain Associated with Minimal Endometriosis

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ABSTRACT

Endometriosis has been examined in numerous ways and, primarily, it presents in two forms: painful, often associated with minimal findings; and non-painful, often associated with marked disease. The focus of this review article is to examine the pain aspect associated with minimal endometriosis.

Key Words: Pain, Minimal endometriosis, Second look.

INTRODUCTION

Endometriosis has a long history, dating back prior to the initial articles by Sampson.¹⁻³ The efforts to describe the lesions associated with endometriosis were followed by several theories⁴ on how the endometrial tissue arrived at the affected organ or peritoneum. Although this has not been fully resolved, the basic problem is that normal tissue is in an abnormal location. A simple analogy that is often used to explain endometriosis to the patient is the example of the eyelash and the eye. The eyelash is a "normal" part of the eye and quite separate from the eyeball. Should a "normal eyelash" be placed on a "normal" eyeball, the eye becomes red with dilated corkscrew vessels. The eye becomes painful but continues to function, though not optimally. The eyeball returns to its normal state once the eyelash is removed. The body reacts in a similar manner when the "normal peritoneum" is exposed to the "normal endometrial tissue." The peritoneal lining develops red lesions with dilated corkscrew vessels and becomes painful. The pelvic organs continue to function but not optimally, which can lead to infertility. The way to cure the problem is to find and remove the "normal endometrial tissue." Although this analogy is not perfect, the patients seem to grasp the concept, since they have all experienced an eyelash in the eye scenario.

PATHOLOGY AND PAIN

Unfortunately, locating and removing the "normal endometrial tissue" has not been as easy as finding and removing the "normal eyelash." In the early method of locating and treating endometriosis, laparotomy was the only approach to access the pelvis. Lesions, located with the naked eye, were biopsied and removed with marginal success⁵ in relieving the pain associated with endometriosis, since lesions, too small to be seen, were left untreated. With the advent of laparoscopy, new lesions were identified,⁶ including red and white lesions. Unfortunately, the identification of these new lesions did not improve the results of therapy to any great degree.⁷ Patients woke up from their surgery stating that there was no difference in the pain, or they had temporary pain relief for 6 to 24 months. More radical therapy,

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including hysterectomy and bilateral salpingoophorectomy, was recommended in the belief that the cramps originated in the uterus, and the endometrial tissue was encouraged to develop under the influence of estrogen from the ovaries. Although this improved the results of therapy, failures were noticed,⁸ and the pelvic pain and painful cramps persisted in many patients. Consequently, it was concluded that the pain and cramps must be of another origin since the uterus was removed. Patients were sent off for extensive bowel work-ups and were left with a diagnosis of irritable bowel syndrome, or were told that the origin of the pain was (“in her head”) psychosomatic.

Researchers persisted to perusing the cause of the pain. Dr. David Redwine⁹ theorized that the pain originated from the peritoneum, and, if one removed the entire peritoneum, the pain would resolve. Success was achieved, but due to the extent of the procedure, the risk of adhesion and subsequent pain was still present. However, a significant finding in the pathology specimens, was that microscopic endometriosis was present in “normal appearing” peritoneum, and this was confirmed by Dr. Dan Martin⁶ and others. Finally, an explanation for the recurrence of the symptoms of endometriosis was found. These microscopic implants in the normal looking peritoneum⁹ were not excised since they were not “seen” and, thus, later developed into larger lesions, with subsequent recurrence of the symptoms of endometriosis.

Pain Mapping of Endometriosis

Further advances in therapy for endometriosis seemed to come to a stand still since there was no method of determining where the microscopic disease subsided. In the last few years, however, the development of new and

smaller technology promoted a resurgence in performing laparoscopy in the awake patient. Smaller micro-laparoscopes and micro-instrumentation, coupled with video-laparoscopy, enabled the patient to be an integral part of the operation, and the patient could interact with the surgeon during the laparoscopy. So dawned the age of Patient Assisted Laparoscopy (PAL)¹⁰ or laparoscopy under IV conscious sedation. Since the patient was the only person in the operating room who knew where the pain started and where it ended, it always seemed illogical to anesthetize the patient leaving the surgeon to tell her where her pain was based upon what the surgeon saw. Wouldn't it be better for the patient to confirm with the surgeon where the areas of pain associated with the endometriosis are located? With the patient's help, the areas of pain associated with the lesions of endometriosis can be “mapped” so that therapy can be based on the patient's input as to where the pain starts and where it ends.

Initial work on mapping of pain¹¹ associated with the endometriosis lesions resulted in some thought-provoking findings. The classic black lesions were found to be painful in only 11% of patients when the lesion was touched. Similarly, white lesions were painful in 20% of patients with red lesions at 37%, and clear lesions at 32% were the most painful (**Table 1**). These results added further reason as to why initial therapy had such poor results. Surgeons would only “see” the black lesions and removed them, but these were the least painful lesions. The most painful clear lesions were not “seen” at laparotomy and therefore remained, as did the pain.

What became apparent next, while mapping the patient, was the fact that the pain extended 28 mm beyond the visible border of the lesion onto what looked like “normal” peritoneum (**Figure 1**). Therefore, if the surgeon

Table 1.
Incidence of Pain versus Type of Lesion.

Type of lesion	Pain present	%	No pain	%
Clear Lesion	38	32	12	24
Red Vascular Lesion	42	37	8	16
White Scar Lesion	22	20	28	56
Black Lesion	11	11	39	78

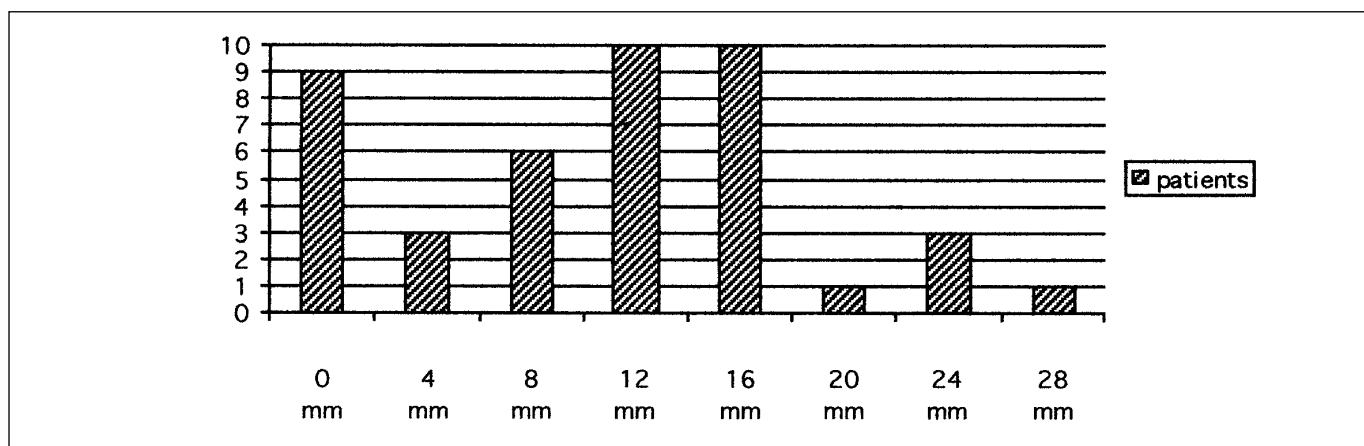


Figure 1. Distance of pain from border of lesion.

only removed the lesion at its border, the microscopic disease in the previously identified normal looking peritoneum was left, and persistence or recurrence of the symptoms was encountered. With pain mapping, the patient can determine, by her pain, where the microscopic endometriosis is so the surgeon can remove it along with the visible lesion.

Characteristics and Location of the Pain

With the patient now being a member of the operating team, and able to verify the findings “seen” at patient assisted laparoscopy, more information about the characteristics and location of the pain associated with endometriosis has been found. In a normal patient or a patient with endometriosis, palpation of the uterus during mapping failed to illicit pain or cramps. Palpation of the lesions of endometriosis produced the cramps, not the uterus. Patients, postoperatively, reported that once they identified the cramps of endometriosis, they noticed that they were different than menstrual cramps. Furthermore, palpation of the endometriosis lesions on patients without a uterus and both ovaries removed reproduced the cramps of endometriosis. This confirmed the findings of other researchers who have concluded that a hysterectomy often does not change the course of the pain of endometriosis since it is the lesions, not the uterus, which are responsible for the cramp-like pain.

The location of the lesion in relationship to the pelvis

can, in most instances, reproduce the symptoms the patient experiences. Lesions on the utero-sacral ligament, when palpated, cause pain or cramps in the back. Palpation of lesions on the side wall of the pelvis result in pain or cramps radiating down the leg. Therefore, during a pain mapping procedure, the symptomatology experienced by the patient can be confirmed to ensure that the lesion causing the pain is properly identified prior to therapy. What is most interesting is that right-left orientation of the pelvis does not exist in some patients.¹² That is to say, palpation of a lesion of endometriosis on the left side of the pelvis may produce pain that the patient perceives as being on the right side of the abdomen, and the opposite is also true. How many times has a laparoscopy under general anesthesia been done on a patient complaining of right-sided pain where the surgeon saw a normal looking pelvis on the right—only to wake up the patient and tell her, “I saw nothing on the right side of your pelvis that would cause your pain.” It now becomes apparent why the results of the survey of the Endometriosis Association’s members revealed that the average length of time from the onset of symptoms to the treatment of the endometriosis was 9.28 years and an average of 2.3 operations.¹³

FRONTIERS OF THERAPY

As has been shown over the years, results of therapy, based only on what the physician sees, is marginal at best, especially in minimal endometriosis (ie, stage 1 and stage 2). With the development of patient assisted

Table 2.

Tolerance of Patients to Mapping and Treatment in Awake Laparoscopy.

65%	Tolerated the entire procedure.
12%	Required a general anesthetic due to pain limiting access to lesion for therapy.
22%	Requested a general anesthetic prior to completion of therapy.

laparoscopy and pain mapping, patient input seems to be essential in achieving better results. Initially, the work done in conjunction with pelvic pain mapping involved mapping the areas of pain associated with the endometriosis lesions and recording the conversation and input of the patient during the operation using a twin-video system with picture in picture. The patient would then be anesthetized after the mapping was completed, and the lesions and areas of pain that were mapped would be treated. Once the operation was complete, the patient was followed up in the office.

After a year of this therapy, a new approach was attempted. This involved keeping the patient awake for the mapping and the treatment.⁵ While awake, the patient could confirm that the therapy was successful when the area treated was remapped, and the pain was completely gone. This approach relied on the patient and the surgeon working as a team to diagnose, map and treat the lesions. Therapy was continued until the patient was satisfied that the pain associated with the endometriosis was no longer present. Although it seems that this approach would be too painful, two-thirds of the patients selected completed the surgery without general anesthesia (Table 2).

FOLLOW-UP AND SECOND LOOK LAPAROSCOPY

Endometriosis follow-up, for the most part, consisted of waiting until the patient complained of recurrence of the symptoms of endometriosis. A repeat laparoscopy was scheduled 6 to 24 months after the initial surgery. This wait-and-see policy did not, in most part, follow the format seen in other medical conditions. Let us take a fractured arm as an example of other medical conditions and

compare it to endometriosis. The investigation for acquiring diagnosis would be a detailed history, physical examination, and confirmation of fracture by X-ray. The patient would be taken to the operating room, the fracture reduced, and a cast placed to ensure proper conditions exist for healing. The cast is removed after six weeks, and the results of therapy are confirmed by follow-up X-ray. Imagine the success rate of surgery if no cast was placed, and there was no follow-up at six weeks to confirm healing, while we waited until the patient returned complaining of a painful arm? This would be unheard of—but isn't this exactly what happens with endometriosis?

Let us see if there is a way of following up endometriosis therapy to the same standard that exists for a fractured arm. Once the tissue in the pelvis has been treated for endometriosis, the rate of healing varies from days for the peritoneum to weeks for the vault and adnexa. During this time, it would seem logical to ensure an environment that promotes proper healing. Researchers, in their analysis of Danazol, revealed that it stimulates the immune system and acts as well in preventing the effects of estrogen on endometrial tissue. Others have reported a reduction in scar tissue and adhesion formation¹⁴ with postoperative administration of Danazol. Therefore, there may be reason to administer Danazol to promote better healing of the areas just as the cast promotes better healing of the arm. A course of Danazol 200 mg B.I.D. for two menstrual cycles, ie, 60 days postoperative, may have some beneficial results.

Following this, the patient is re-examined after six weeks. After completion of the Danazol, she is asked to keep a diary of her cycles once they return. This will give her an indication of what she should expect for her normal periods. Since she has been abnormal for so long, she does not necessarily know what is normal for her. The diary would help her in this aspect. The patient is also informed that she may have been splitting her abdominal muscles in response to the pain. Once the pain is no longer there, she may experience various abdominal muscle spasms, as the muscle returns to a full range of movement. This is similar to what the patient experiences after the cast is removed from the arm.

The final chapter in this approach to management of the pain due to endometriosis is to confirm with the patient that the pain has completely gone. A more aggressive and objective approach is required to convince the

patient, who may have spent years reading about endometriosis, years of talking with other patients with endometriosis, and years of failure of therapy, that her pain related to endometriosis is really gone. To do this, a repeat patient assisted laparoscopy and re-mapping of the areas treated is necessary. In this way, the patient herself, not the surgeon, confirms the results of therapy. The end point in mapping is that there is no pain where the treated areas are mapped, or that there is no difference in sensation between normal areas of peritoneum and the treated areas. This approach is as effective as the surgeon showing the follow-up X-ray of a fractured arm to the patient and pointing out how well it has healed. Just as the X-ray gives the patient the confidence to go out and use the arm, the second-look patient assisted laparoscopy gives the patient the assurance that every cramp or pain is not her endometriosis returning.

It seems a lot to ask a patient, and an insurance company, to go through a second-look patient assisted laparoscopy. The need for the patient to know, and the reduced costs of return visits for pain and other investigations to rule out possible recurrences, outweighs the costs of a second-look procedure. This approach only asks that endometriosis treatment and follow-up be similar to other diseases.

CONCLUSION

Since data is still in its infancy, one may criticize this approach to the diagnosis, treatment and follow-up of pain associated with minimal endometriosis. The data revealing the failure of the approach of "treat and see," based on what the surgeon observed at laparoscopy under general anesthetic, is strong and reveals that a new approach is needed. An approach based on patient confirmed diagnosis and patient-based analysis of the results of therapy needs to be looked at in greater detail. The only person who knows where the pain starts and ends is the patient herself. She is also the only one who can confirm when the pain is no longer present.

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